

End-of-Life Resource Use

Summary: This project aims to understand how resources, including hospitalizations, hospice, home care services, are utilized at the end of life and the relationship with site of death and costs.

Section: Ethics and Health Policy—Unit on Bedside Ethics

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Background: Over the last 2 decades, there has been much controversy about spending at the end-of-life. The concern has focused on several key perceptions: costs of care at the end of life are very, very high, about 27% of all Medicare expenditures; deaths are too “high-tech” and de-personalized; and comfort measures, such as hospice, are under-utilized. Unfortunately, there are woefully few data on costs and resource utilization at the end of life. The last analysis of costs at the end of life reported on Medicare costs from 1988. The last analysis of the use of hospice at the end of life and its effects on costs report on data from 1992 and only reported on Medicare cancer decedents. These data have major deficiencies in that they pre-date:

- The substantial efforts to reduce hospitalization rates and length of stay
- The substantial growth of managed care
- The substantial focus of national attention on improving care at the end of life and use of hospice.

Furthermore, almost all available data come from Medicare and therefore focuses on the resource utilization of decedents over 65 years of age. Fully one third of all decedents in the United States are under 65.

Objectives:

- 1) To describe costs, resource utilization, and site of death of decedents.
- 2) To describe how costs, resource utilization, and site of death vary by payer types, that is by whether the decedent had fee-for-service or managed care coverage.
- 3) To describe how costs, resource utilization, and site of death vary by the cause of death, socio-demographic characteristics of the decedents, and hospice use.
- 4) To describe use of chemotherapy at the end of life for cancer decedents.
- 5) To describe how hospice is used at the end of life.

Methodology: Initially both Harvard Pilgrim Health Care—a managed care organization with both a staff model component and an IPA component—and Massachusetts Blue Cross and Blue Shield thought they could provide expenditure data on all their decedents. Both those covered in managed care programs and those under 65 years of age. Unfortunately, after working with both organizations for over a year it became clear that they either did not have the expenditure data or did not collect the expenditure data linked to mortality in a format that could be analyzed. Instead, we relied on 1996 Medicare data from Massachusetts and California.

We merged Medicare's denominator files with each state's 1996 death certificate files. Only beneficiaries continuously enrolled in both Parts A and B Medicare insurance over the entire last 12 months of life were retained. In Massachusetts, 42,452 Medicare decedents met the criteria. In California 20% of decedents were used comprising 33,684 people. Decedents were divided by their insurance status into three groups: 1) those continuously enrolled in a fee-for-service (FFS) plan for the last 12 months of life; 2) those continuously enrolled in a managed care organization plan (MCO) for the last 12 months of life; and 3) those that changed between FFS and MCO during the last 12 months of life. Total expenditures were calculated as the sum of HCFA payments and payments from other sources of insurance for Medicare covered services. We examined expenditures, services provided including hospice and chemotherapy use for decedents for 30-day periods from the date of death back 12 months.

Results: Because of the inability to obtain data from Harvard Pilgrim Health Care and Massachusetts Blue Cross and Blue Shield, the objectives of describing costs and

resource utilization by payer type and for decedents under 65 years of age could not be achieved.

Some of the most salient results can be summarized as follows:

- Expenditures over the last year of life are on average \$28,588 for Massachusetts decedents and \$27,814 for California decedents (1996 dollars).
- Patients dying of COPD have the highest expenditures--\$35,145 in Massachusetts and \$33,269 in California—and patients dying of cancer having the second highest expenditures.
- Expenditures rise exponentially as death approaches, with the last month of life accounting for approximately 32% of the entire last year of expenditures in Massachusetts and 38% in California.
- Overall hospice is still predominantly used by cancer patients. In Massachusetts 70% of all hospice patients have cancer, in California 60%. Indeed, in Massachusetts 33% of all cancer patients receive hospice and just under 50% do so in California.
- Managed care patients are much more likely to receive hospice care at the end of life than patients who have fee for service insurance.

	Massachusetts		California	
	Fee for Service	Managed Care	Fee for Service	Managed Care
% receiving hospice	11.0%	16.6%	15.9%	25.2%
% hospice dying in-hospital	11%	NA	5%	NA
% non-hospice dying in-hospital	43%	NA	43%	NA

- There is a substantial reduction in expenditures and resource utilization with an increasing in age. This age based rationing is not accounted for by co morbidities.

	Massachusetts			California		
	65-74	75-84	85+	65-74	75-84	85+
Expenditures in the last year of life	\$35,300	\$30,900	\$22,000	\$34,300	\$30,300	\$21,600

Hospital days/1,000	2,044	1,854	1,432	1,871	1,664	1,273
ICU	25.6%	23.7%	15.9%	29.4%	28.4%	22.0%
Respirators— as % of those in ICU	35.7%	32.8%	24.2%	30.5%	27.1%	21.4%

- There is a reverse racial disparity in expenditures at the end of life: African Americans receive approximately 50% more resources in the last year of life compared to whites. In Massachusetts, expenditures in the last year of life for whites was \$28,200 and for African Americans \$42,200, in California for whites it was \$26,300 and for African Americans \$40,700.
- A substantial proportion of patients who die of cancer receive chemotherapy at the end of life. In Massachusetts 33% receive chemotherapy in the last 6 months, 23% in the last 3 months and 9% in the last 1 month of life. Similarly in California, 26%, 20% and 9% respectively.
- Chemotherapy use is similar for cancers that tend to be chemotherapy responsive and those that tend to be chemotherapy unresponsive. However the duration of chemotherapy use is lower for unresponsive cancers.

	% Receiving chemotherapy in last 3 months of life	% Receiving 1 month or less of chemotherapy
Breast	22%	32%
Colon	23%	35%
Ovarian	30%	29%
Pancreatic	25%	49%
Hepatocellular and Gallbladder	20%	59%
Renal Cell	22%	51%

Future Directions: These data are limited in two main ways: generalizability and age of the data. Furthermore, one of the most intriguing results, the disparities in the use of resources at the end of life according to race, were based on very small numbers. To address these limitations and to focus on the racial disparities, we are preparing to

create a national database of Medicare claims data to include 60,000 white decedents, 60,000 African-American decedents, 60,000 Hispanic decedents, and 570,000 randomly selected Medicare beneficiaries who are alive. The decedents will be linked to the National Death Index to obtain information on underlying cause of death and site of death. The data will be based on patients who died in the year 2000 and therefore will cover one years of claims from the years 1999 through 2000.

First we intend to make this a public database to facilitate research on costs, resource utilization, and patterns of care at the end of life. Very little research of this type has been done because the cost of assembling such a database is very large. With a total of 180,000 decedents and 570,000 living patients for comparison this will be a very rich database.

Second, the Department and its collaborators will focus their project on three objectives. We will explore the hypothesis that there is an inverse racial disparity with African Americans and Hispanics receiving greater expenditures and resource utilization at the end of life. We will then try to determine potential causes for this disparity. Potential explanatory variables include greater hospitalization rates at the end of life, decreased use of hospice and home care services consistent with documented decreased tendency of African Americans to complete advance care directives and fewer family supports at the end of life. Other potential explanatory variables are more co-morbidities requiring multiplicity of health care services. If this “reverse racial disparity” is confirmed it would represent a significant misallocation of resources regarding the health care of minorities, especially African Americans. Much research documents that African Americans have lower health care expenditures and receive fewer health care resources, such as cardiac catheterizations, renal transplants and screening tests. If our research demonstrates that they have 50% greater expenditures during the last year of life, then the system is providing African Americans the worst of all worlds—probably total life time expenditures that are similar to whites but with fewer services when they might be effective in prolong life and reducing morbidity and greater resources at the end of life because of greater hospitalization.

Another major study will seek to describe in more detail hospice use at the end of life. We understand that most hospice patients are cancer patients, but most receive hospice services for 3 weeks or less. In general, the short hospice stays compromise quality of care and also have minimal effects on expenditures. We will try to determine if there are any predictors of longer hospice stays, whether the primary determinants are patient characteristics, demographic characteristics, such as location, or seem to be linked to particular physicians. Furthermore, we will examine how length of stay influences expenditures.

Finally, the data from Massachusetts and California suggest important trends in the location of death. In 1996, in these states, approximately 40% of deaths were in-hospital. This appears to be a dramatic shift out of the hospital. To document this shift and determine predictors of this shift, we will examine data on site of death from the National Death Index from every state in the United States and examine whether

geography, sex, age, cause of death, availability of hospice, or other factors are associated with greater shifts toward out-of-hospital deaths.

Publications:

Levinsky NG, Yu W, Ash A, Moskowitz M, Gazelle G, Saynina O, Emanuel EJ. Influence of Age on Medicare Expenditures and Medical Care in the Last Year of Life. JAMA 2001;286:1349-1355.

Emanuel EJ, Ash A, Yu W, Gazelle G, Levinsky NG, Saynina O, McClellan M, Moskowitz M. Managed Care, Hospice Use, Site of Death, and Medical Expenditures in the Last Year of Life. Archives of Internal Medicine 2002;162:1722-1728.

Emanuel EJ, Young-Xu Y, Levinsky NG, Gazelle G, Saynina O, Ash AS. Chemotherpay Use among Medicare Beneficiaries at the End of Life. Annals of Internal Medicine 2003; (in press).